

ALTOGETHER  
AUTISM  
TAKIWĀTANGA

Transitions  
Through  
The Life  
Stages



ALTOGETHER AUTISM  
**JOURNAL**  
2022



Altogether Autism is a free, nationwide autism information and advisory service provided as a partnership between Life Unlimited and Parent to Parent New Zealand.

With the vast amount of material available online, finding credible information on autism can be a challenge.

Altogether Autism provides tailor-made, relevant, evidence-based information, individually researched and collated by our information and research team.

Our team has the skills and experience to provide trusted information and can refer your more complex requests to our Advisory Group. This Advisory Group includes autistic people, family/whānau and professionals.

Whether you are autistic or you are family/whānau or a professional supporting an autistic person, our service is free.



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# Transitions: from the Beginning to the End



Nau mai, haere mai, welcome to our 2022 edition of the Journal. As I write this, Queen Elizabeth II has just died, the Covid 19 traffic light system has come to an end and Paula Tesoriero has been appointed chief executive of Whaikaha – Ministry of Disabled People.

Paula is the first disabled chief executive of a government ministry and we are hopeful this will see meaningful change. Here at Altogether Autism, we are not waiting for Whaikaha to lead the change, but continue to do all we can to be the change we want to see.

To this end, we greatly appreciate the work of our 12 advisors, a mix of Autistics, family/whānau and professionals. These advisors guide our strategic goals each year, and provide invaluable advice when you contact us with complex information requests.

We welcome Maia Kawana to the Advisory Group; you can learn more about Maia and his family in this edition of The Journal. Tēnā rawa atu koe i tō mahi Maia – thank you so much for your work Maia.

One of our foundation advisors, Tanya Breen is now Dr Tanya Breen, after being awarded the degree of Doctor of Health Science in July. Our congratulations on this milestone Dr Breen and for the important contribution of your research into the experiences of autistic people suspected, charged or convicted of criminal offending.

We also welcome researcher Christina Forrest to our team. The researchers are responsible for researching your complex requests and liaising with the advisors, to ensure lived experience informs our responses to your requests, published research and professional guidance. This free service is the only one of its kind in Aotearoa New Zealand, so please contact us with your requests, no matter how big or small.

We have developed a new free workshop for our network meetings. Brain, Body and Behaviour offers insights and strategies to support both parents and children. It draws from leading child psychologist Mona DelaHooke's latest book, Brain-Body Parenting. Check out the back cover for more information and visit the events page of our website for dates and locations, including an online option.

I hope you enjoy this edition of the Altogether Autism Journal themed on transitions. Many thanks to all the contributors.

Ngā manaakitanga – with best wishes,

**Catherine Trezona** *National Manager, Altogether Autism*



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## Tertiary Journey Made Easier for Autistic Students

It took **Rachael Wiltshire** nine years to complete her tertiary education, but it could easily have taken half that time if she knew then what she knows now.

Rachael, 28, graduated last year with a Bachelor of Creativity in Commercial Dance from Te Kāhui Auaha in Wellington and currently dances at events around the capital.

Her educational journey as an autistic student was fraught with challenges and she is now using what she learned to help other students facing similar predicaments.

The Altogether Autism autistic advisor has helped research and write six guides commissioned by the Tertiary Education Commission aimed at lecturers and tutors in tertiary institutions to understand what autistic learners need from them while studying.

"We surveyed 99 autistic tertiary students and whilst their comments often made for harrowing reading, it was also validating to see that I was in no way the only person who had struggled in these ways," said Rachael.

Altogether Autism analysed the results and concluded the most critical areas that required more support and understanding in tertiary institutions were around communication needs, executive functioning and self-advocacy.



Family/whānau also commented strongly on the difficulties in finding and accessing support, and the lack of understanding and knowledge for anxiety and mental health issues.

The guides appear on the Altogether Autism website in printable versions with four student profiles and an article on how one special education needs coordinator (SENCO) made the journey to a tertiary education easier.

Rachael said one respondent summed it up by saying "assume everyone is trying their best and wants to do well."

"If you can keep that in mind and respond with compassion when students reach out for help, you will make a big impact in terms of autistic students having a positive experience of tertiary education," she said.



*Rachael Wiltshire lives in Wellington and found out she was autistic when she was 12. She has been passionate about autism advocacy ever since and has spoken at several conferences. She is an autistic advisor for Altogether Autism.*





# Successful and Smooth Transitions from Early Childhood Education to School

Who finds transitions or changes easy or convenient, asks speech language therapist **Estelle Pretorius**? At the best of times, it takes bravery, skill, practice, planning and time to process.

**EARLY TRANSITIONS** can be successful and seamless when time is dedicated to preparing for the shift and keeping the child at the centre of the transition.

Transitioning autistic children from early childhood education into a school setting is significant and can involve anxiety and concern for primary caregivers.

For these transitions to be successful, they require thoughtful planning and consideration.

The most important thing to keep at the centre of the transition is the subject of the transition: the child.

When we do so, the planning and preparation are individualised to the child's needs, strengths, and interests.

Two of the key recommendations in the recently published New Zealand Autism Spectrum Guideline Supplementary Paper on Transitions (Broadstock, 2019) address person-centred transition planning.

Children's voices, preferences, and strengths should be front and centre when guided through significant changes.

This recommendation is echoed throughout the Guidelines (Ministries of Health and Education, 2016) but also heard in the perspectives of parents and caregivers (e.g., Stoner et al., 2019) and in the national guidelines for best practice in early childhood intervention (ECIA, 2020).

Can we imagine how different such a critical transition would be if a child's strengths, interests, preferences, and support needs were at the centre of all planning, preparation, and communication, related to their transition into school?

A successful transition is child-centred, family



and whānau-focused and offers wrap-around, coordinated support from practitioners, educators, support people, and other systems for support (see figure 1).

### UPDATED GUIDELINES FOR TRANSITIONS

The supplementary paper on school transitions provides updated guidelines for successful transitions into and between primary and secondary schools and within year levels. This paper provides a set of recommendations relating to school transitions and good practice points. (See Summary recommendations, next page)

When adopted, these recommendations can lay a strong foundation for your child's successful start to their formal education. Though each school transition may take on a different pathway to success, some principles remain essential; informed decision-making, person-centred and shared planning for individualised support, and a strong culture of relationship building and belonging.

### INFORMED DECISION MAKING

Pick a school that is willing to grow with your child and adopts an outcomes-based approach. Understanding a school's inclusive culture and practices is extremely helpful when choosing a school for your child.

Your partnership with the school around your child's strengths, skills, preferences, interests, support needs, and goals will be integral to their belonging and settling into a school.

Begin to connect with the school community, understand its people, volunteer, and offer your expertise to the school, and embrace opportunities to learn about the school's culture through events.

Learn about the school's values by searching their school web page, scheduling an appointment with key educators at the school and asking questions about their approach to children with additional learning needs.

A school that endorses family-centred and strengths-based values and adopts an outcomes-based approach will set you up for a successful transition and a sustained positive partnership that will allow your child to master skills and flourish in relationships.

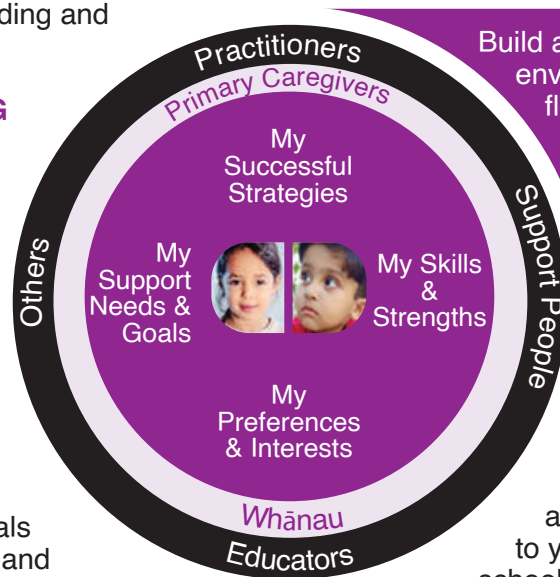
### PERSON-CENTRED PLANNING

Introduce your child and family to the school. Develop a pack of resources to help others understand and learn from your child.

Share your expertise about your child and the tools that have been successful in your child's early education, in the community and at home. Co-develop these resources with other key adults that know your child well.

Allow them to learn about your child's interests, preferences, and strengths by observing your child in various settings and regularly connecting with familiar supporting adults such as the child's early education team or any support workers with whom your child has an established relationship.

Give your child a voice by asking him or her about the things they enjoy or dislike, things that make them anxious, and things that make them feel calm or organised. Visual communication strategies such as self-regulation charts, emotion thermometers, picture choices, and personal stories may help your child inform the school about their preferences.



Build a repertoire of activities and environments where your child flourishes; this information would be valuable for the school to know. Setting the school up to know as much about your child as possible is an essential first step.

### SHARED PLANNING FOR INDIVIDUALISED SUPPORT

Understand your child's support needs. Discuss available support with the school and ask how accessible it may be to your child. Collaborate with the school around supports and strategies you already have in place and work together to establish these in your child's new setting. Allow time for educators and practitioners to learn from your child about what his or her needs or goals could be at school. Work with the school to plan as many opportunities as possible for your child to work towards these goals across the school setting, the school community and home.

Develop a coordinated plan with the school to meet your child's support needs. Co-create a safe, calming, and conducive learning environment for your child. Partner with the education team to create a safe space designed with the child rather than for the child.

Consider how the classroom setting, the outdoor play areas, and the social opportunities can be modified or enhanced. Clear and concise communication about the action plan, timeline, roles, responsibilities, and social supports will ensure your child has the best possible start in their new learning environment. Most importantly,

*Story continued on next page*



establish a shared review process that reviews your child's support needs, successes, and preferences.

## RELATIONSHIP AND BELONGING

Establish your child's belonging in the school by connecting them with the school community and social supports. Find out about peer groups connected to your child's interests and work together to integrate your child successfully into this group.

Observe your child during playtime and learn from the choice he or she makes. Develop a plan where they can engage in regular opportunities to connect with a peer group and feels acknowledged and included.

Recognise that your child may have anxiety about engaging with others at school and work with the teaching team to recognise the triggers, minimise the environmental triggers where possible, and provide support to succeed during these interactions. Early success in peer groups will have long-term positive outcomes for your child at school. Also, as parents, reach out to resident families and create a peer support group where you can share ideas, experiences, and expertise.

## CONCLUSION

The key to any successful transition is to trust the process, explore the possibilities together, and celebrate the differences. This is especially relevant during transitions early childhood education to a more formal school environment.

Keeping the child at the centre of the transition and building strong community and wrap around support, will create a safe place to explore change and possibilities together.



*Estelle Pretorius is a member of the Altogether Autism Advisory Group. She is also a speech-language therapist and doctoral student at Massey University.*

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## Summary Recommendations

1. Establishing a key education professional early in the process for support, guidance, and ongoing point of contact.
2. Person-centred planning, that is, involving children and young people in the decisions by respecting their views and individualising plans based on their preferences.
3. Regular team transition meetings, prior to and throughout the transition, involving whānau, key staff and supporting team members.
4. Co-developing a student profile based on the child's strengths, preferences, needs, behaviours/skills, interests, and successful strategies.
5. Transition visits for the child to alleviate anxiety, establish familiarity and to offer opportunity to establish key relationships early in the process.
6. Using individualised visual supports when appropriate.
7. Planning for social supports and environmental adaptations.
8. Maintaining regular, constructive, and culturally appropriate and respectful communication.
9. Sharing support strategies across home and school environments.

■ *For access to the complete resource: NZ Autism Spectrum Guideline Supplementary Paper on School Transitions, 2019*







# Preparing your Child to Transition to a Mainstream School

Going from an early childhood provider to a mainstream school can be a difficult transition, writes **Maia Kawana**.

We, like so many parents, wondered how our two sons were going to cope with school after their time at kindergarten.

The transition is a time that can create a significant amount of stress and concern for parents.

The gaps between your current kindergarten provider and a mainstream school may seem too far to reach.

We learned many lessons about transitioning our autistic children into a mainstream primary school and our recommendations follow.

## GETTING STARTED

Schools have a daily structure and routine that can be a substantial change for our kids.

If your kindergarten already uses daily structure for meals, playtime, mat time, etc, then the transition can be a bit easier.

But if it does not, the change to school will be more difficult for your child to get used to.

Try to get your child into a routine for different activities. A consistent time for morning tea, lunch, afternoon tea, as well as activities such as reading time, playtime, etc.

We were fortunate that our kindergarten already had a strict daily routine which is one of the reasons why we chose it. Our kids respond to routine well and like to do the same things at the same time.

The key thing is to get our kids used to a routine; create a timetable and put it somewhere the kids can refer to and remind them by using the timetable when activities are going to happen.

This can be like any family routine that you use in the evenings or weekends. Ask your school for a timetable that you can simplify to show your child so they can begin to learn and refer to.

## INDIVIDUAL EDUCATION PLAN

You may already have an Individual Education Plan for your child at kindergarten, and if you do not, it may be a good idea to begin one.

It is simply an agreed list of goals and activities created by parents, teachers, and your early childhood intervention centre key worker.

I will use 'key worker' several times in this article.

A typical goal could be to learn how to hold a pencil, write their name, eat a different fruit, use the bathroom, play with other children, etc. This is customised for your child and their own unique challenges.

*Story continued on next page*



Your transition to school plan should be making use of your Individual Education Plan with key goals preparing your child for school.

### SCHOOL PASSPORT

A School Passport is a unique document you create to inform the new school, teachers, other students, and other parents, about your child.

It can be as long or short as you feel but should cover some key points about your child to help others understand your child better.

You may include a photo, their favourite toy/teddy, favourite colour, favourite food/meal, what their family looks like, any pets, what games they like, things they do not like to do, and things that may upset them.

It is a document used to educate the school, so they are better prepared for your child.

Your kindergarten and key worker could be offered the opportunity to provide feedback as they may offer some good advice for the schoolteachers.

### ADDITIONAL DETAILS

Ask your kindergarten if they are happy to provide either a written or verbal overview of your child to the new school's key teaching staff.

Kindergarten and schoolteachers may share common terminology and processes within their respective professions.

Thus, there may be key insight shared between both professionals if they are happy to discuss before the transition takes place, or even during the transition phase.

### ONGOING RESOURCING SCHEME FUNDING

Your key worker will discuss with you the Ongoing Resourcing Scheme funding and application process.

There is a lot of information required and the process does take time, so ensure you are working on this process with plenty of time.

The process is better discussed with your key worker, but there is one key question that you will need to consider; what if you do not get the funding? Or the funding is less than you expected? If you are unsuccessful with Ongoing Resourcing Scheme funding, then you are part of a group of many other families that must find solutions to support their child outside the process.

This is best discussed with your selected school as to what other options may be available for funding. This also depends on the number of resources your selected school already has in respect to teaching assistants and other teaching support resources.

This can be a key question that you ask your potential schools when you interview them.

### VISITING POTENTIAL SCHOOLS

I do not have any experience of special schools and will continue to focus on mainstream schools instead.

You will need to do some homework on the geographic zoning for your current residence.

This will provide the initial options for schooling. However, do not be afraid to select schools outside your zone, and contact them to ask if they would consider your child.

The worse that can happen, is they say 'no.' We had two local primary schools that our child could apply to, but we also chose two other primary schools outside our zone, and we wrote to the principal asking for an opportunity to meet and discuss our child potentially attending their school.

We were pleasantly surprised when they both agreed to meet with us for an interview.

You should have a few interviews to compare schools, resources, strengths, weaknesses, and the attitude of the school leadership.

We approached the selection and interview process with a different attitude; we want to choose the best school for our child, not a school willing to accept a child with specific challenges.

Expect the best for your child and ask potential schools to put forward the 'value' that they can add to your child's specific development.

There are other resources you can use to select schools, such as talking with other parents and using online resources that provide information about the schools you want to interview.

### PREPARING FOR THE VISIT

The school visits should be set up formally by your key worker.



Try not to have your child at the initial school visit as you need to be focused on the discussion you are about to have.

Both parents (if applicable) should attend as well as the key worker.

You could choose others but try not to have too many attending.

From the school, it would be better to have both the principal and a key teacher involved.

The principal will give you a good idea of the culture of their school, particularly, the attitude towards children with special challenges.

Preparing your questions is vital in helping you choose the best school for your child.

Remember, no one knows your child better than you. You need to cover any items of concern you have that are unique to your child, along with educating the school as to essential information they need to be aware of.

Key questions may include security, fencing, teacher assistant resources, class sizes, Ongoing Resourcing Scheme funding, etc.

After each school visit it is especially important that you and your key worker document the positives and negatives.

Documenting how you felt about the meeting immediately afterwards is important when comparing the schools at a later stage.

We wrote down our thoughts in the car immediately after each school visit.

You should avoid selecting the school until all meetings are completed and documented.

Write an email of thanks to each school for their time and consideration.

## PREPARING YOUR CHILD

Once you have selected your child's new school, begin talking about the new school as much as possible.

Let your child get used to the idea of an exciting new place to go.

Ask other members of your family and friends to also talk about the school in an exciting and comforting way.

Include their new teacher and new kids to play with, along with new toys to play and new books to read.

Look for reasons to drive past the new school on weekends and wave out or honk the horn to say 'Hi.'

## VISIT SCHOOL

Ask for permission from the school and go for a walk around the school grounds on the weekend.

Play on the playground with your child, walk around the school buildings, and show your child the pickup and drop off points.

Let your child see how excited you are about their new school, and they will feel more interested and accepting of their new adventure.

Set up 'play dates' with other children that go to the school so that your child will know a familiar face during their first few days.

Setup a school visit with your child, new teacher and principal, if possible, before their first day at school.

Show your child their new class, where they may sit or put their bag, where the toilet is, and where their 'safe' place is. I will discuss the 'safe' place further in this article.

## PREPARING YOUR SCHOOL

- > Connect your kindergarten to the new school. Any extra advice could be a significant help to your child's new teacher.
- > Share your updated Individual Education Plan with the new school, particularly your child's new teacher and with the principal.
- > Develop it after the first month and use it as the base for your child's new school plan and setup regular Individual Education Plan update meetings and update it regularly after that.
- > Share your child's School Passport with your child's new teacher and principal. Allow them time to ask questions before your child starts school.

Our school read out our child's passport to the class before he started and tried to prepare the children so they could welcome our child and make him feel more comfortable.

*Story continued on next page*



### SAFE PLACE

It may be useful to create an area in the school to be used as a 'safe place' for your child, should they need to be on their own to regulate or find quiet time.

This place should be away from other children, quiet, safe, and secure.

Include some of your child's favourite items to help them calm down or feel safe when they need to.

We chose the library as it was next to our child's classroom, and only one door down the hall. We placed our child's beanbag and a favourite teddy in there, so they could calm down with some familiar items.

Other options to include could be headphones with music, ear plugs, etc.

### ATTENDANCE PLAN

Agree with the new school on a plan of attendance for your child, for at least the next month.

This plan is unique to each child and should be discussed with your key worker's involvement.

The intent is to gradually increase your child's attendance at school over a period.

### ONGOING RESOURCING SCHEME FUNDING

Keep your school updated on the Ongoing Resourcing Scheme process and any decisions.

Once you know, discuss it with the school and what other options are available if your funding application was unsuccessful.

Each school will be different with regards to the resources that it can offer, so this conversation is unique to your child and the school.

### CONCLUSION

The transition to school can seem like a mountain too high to climb, but all parents must face it, and its best to try one step at a time.

Take comfort in the fact that many other parents have embarked on this journey with the same fears and concerns.



## A Spectator No More



**Sophia** may be the new kid in class, but she is teaching everyone that change is not always a bad thing for autistic ākonga, writes her mum, and ally, **Rebekah Corlett**.

In preparing for this article, I asked Sophia, 13, what she thought of her first term at college. She used her AAC (Alternative and Augmentative Communication) device to tell me:

"I like school. School likes Sophia"

And with that, all the sleepless nights around the decision to transition Sophia from a specialist primary school to a mainstream college just melted away.

Those six little words encapsulated not only Sophia's openness to change, but also her self-awareness that her new school was a welcoming and respectful space for her.

Six glorious words shouted out via her AAC talker, once again showing me and everyone around her that she doesn't need anyone to speak for her.

I look back at most of the time Sophia spent in specialist school with great fondness.

She started as a small, quiet, cautious new entrant. Everything startled her, so we were 'thankful' when the local mainstream school principal pointed us in the direction of the local specialist school,



who offered us all the support we could imagine. Maybe I should've fought harder for a place for her in the local school - we had every right to enrol her at that school. But then again, our journey in education would have been vastly different, with more physical, sensory and attitudinal trauma to move past. It prepared her for this important moment of transition.

Specialist school felt like a loving, but sometimes restrictive, barrier of bubble wrap around Sophia. As she got older, she grew in confidence using her AAC talker to help navigate her way through the world, her need for space increased.

Around the age of 11, it was clear to me that Sophia wanted to explore the world outside of the bubble, and experience new things. She had a voice and knew how to use it. As the end of primary school years neared, I was warned off considering a mainstream option – that they wouldn't tolerate Sophia's loud verbal ticks disrupting the other students. Startled (but undeterred) we went for a visit to the mainstream college next door.

I spotted a portrait in the lobby of the Disability Commissioner Paula Tesoriero on the College's past students wall of honour. A Paralympian and a champion for disability rights celebrated alongside Hollywood director and All Blacks felt like a sign we were on the right track.



The classroom we visited was so calm - teens sat on bean bags, couches, at desks doing their work – with headphones, fidget toys, independently or with an aide.

Sophia walked straight into the kitchen, where she joined in a baking lesson with some other students. Out of the window I could see Sophia's beloved rakau, that she greets every morning on her way to school. I liked the idea that she could still see her old friend swaying in the breeze if she ever needed reassurance.

The teacher was bright and friendly, and made it clear right from the beginning that their class was inclusive, and students could come and go as they please, with as much or as little support as they require. The teachers would be guided by Sophia's individual needs and were excited to learn more about AAC. It was music to my ears!

## RANGATIRA : TRAILBLAZER

Sophia is a Rangatira, a trailblazer – signalling the way forward for everyone around her. She is showing her teachers how AAC is a valid form of communication, and that 'non-verbal' doesn't mean she has nothing to say (quite the opposite!) Sophia is showing us parents that there is no cap on her potential, she just needs time and space to show us what she can do. She is signalling to everybody that she is an active participant in the community, not just a spectator anymore.

So, I took the plunge and enrolled Sophia in a mainstream college. I knew we were leaving behind all the access to therapy team input that specialist school offered, but I also knew that the social benefits of a mainstream environment would outweigh all of this. It just felt like it was time for Sophia to navigate her own waka, steer her own journey into education and teenage years.

It has been a period of transition for all of us. New timetables, new uniform, new staff, new approaches to learning, and I'm happy to say Sophia has taken to it like a duck to water.

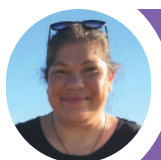
In the first few weeks school was flexible with attendance, uniform items and let Sophia guide them on how much of the timetable she could handle. I kept the before/after school routine calm and non-demanding, so she can start the new day relaxed and refreshed.

Sophia is really enjoying subjects like food technology, Māori and dance. Though the lack of te reo function available in AAC may eventually become a barrier to her engagement in the future.

She loves weekly trips to a farm where the class plant trees, stack firewood, build rabbit fences and care for the animals. This term she used AAC to write an article for the college newsletter. She also took full part in a kapa haka competition with her form class.

Sophia has friends, they have secret handshakes and chat over the lunch table. There's a level of unconditional respect, that they are all the same but different. Her peers are allies as well, which is wonderfully empowering.

Sophia totally embraced the challenge of a new school, a new style of teaching. I'd like to use the phrase that she is 'blossoming' in front of my eyes, but that feels too sedate. Sophia is fireworks exploding in the night sky. The bright colours and patterns are a thing of beauty you can't turn away from.



*Rebekah Corlett MNZM is a member of the Altogether Autism Advisory Group.*



# School Drop-Off Anxiety - Planning for Success



The school drop-off can often be a time of stress and anxiety, writes researcher **Emily Acraman** for both the child and the whānau.

Setting autistic students up for a successful school day starts with the planning.

Whether starting school for the first time, changing schools or classrooms, returning after holidays, or adjusting to COVID-19 protocols, we have some hot tips for making mornings easier.

It can be difficult to differentiate between anxiety caused by being separated from a parent or caregiver, or anxiety about school in general.

Establishing the cause of the anxiety is important, and can be supported through solid relationship building, and creating a safe and comfortable space for the student to communicate this.

Alongside this, is the importance of easy and regular communication between key school staff, the student, and their whānau to ensure they are reading and listening to the student well. Often apprehension about school in general can present as separation anxiety.

One of our advisors recalls:

*"When I was a younger teenager, I used to have meltdowns about school drop off which I guess could have looked like separation anxiety from the outside. But I wasn't anxious about being separated from my parents, I was anxious about being at school".*

## CREATING A CONSISTENT MORNING ROUTINE

Beginning the day in a state of calm, as opposed to chaos, is important for successful transitions to school.

This starts at home and can be aided by the establishment of a clear and simple morning routine. For example, introducing a visual checklist of what needs to be done before leaving the house (i.e. having breakfast, brushing teeth, getting dressed etc).

At school, the unstructured times of the day are often the most challenging for autistic students (before and after school, break times etc). One of the ways to support is having consistent and predictable routines.

If the student is aware of the social and behavioural expectations, and has a clear routine to follow, this may help to alleviate some of the anxiety at drop-off time. The more prepared the student is for what the environment looks, feels and sounds like and how it performs, the more they can plan what they will do when they get there.

One of our advisors describes;

*"The unstructured times at school are really scary. I hated any part of school that didn't have structure as it required social skills and knowing what to say and do, and it was a chance for kids to be mean to each other without teachers paying attention"*

## SUGGESTIONS FOR SUCCESSFUL MORNING ROUTINES INCLUDE:

- Drop offs at the same time, by the same person
- Having the same teacher or educational professional greet the student when they arrive
- Follow a morning routine list, e.g. put books away, hang backpack up etc
- Use visuals where possible to reinforce this routine
- Having a choice of preferred activities for the student to engage in
- Incorporate a preferred activity

Incorporating the students' preferred activity/activities in the morning routine is a great way to alleviate anxiety and helps to set the day up nicely.

Understanding the students' preferences and giving them a choice of what they would like to engage in helps to make school a welcoming and non-threatening environment. Examples of this could include card games, reading, screen time, or giving the student a job (preparing for the day, or putting books away in the library etc).



Our advisors suggest:

*“Setting up some structured fun activities that people can do before school- for example, having some games in the library or a before-school club focussed on something that piques the student’s interest could be a good idea. As I got older, I ended up having a couple of subjects where we had to take an extra class before school started, which meant I got to school and went straight to class- no annoying socialising involved! And when I was in year 6, our classroom maths box had lots of card decks that we would play with before school. That was good because you could just sit and watch people play and only join in if you wanted to”.*

## PROVIDING A SAFE SPACE

Another strategy that has been suggested by our advisory members, is having a safe or quiet space to retreat to before school starts.

One of our advisors mentions:

*“When I was in years 7 and 9 and was really anxious about school drop-off, my parents used to walk me to the dean’s office and I would then sit quietly in the dean’s office until it was time for class to start. This meant I was being directly handed over to someone who could keep an eye on me so I couldn’t try to escape, but it also gave me a quiet space to adjust to the school environment, a chance to talk to the dean about anything that was worrying me, and it meant I could avoid the sometimes challenging before-school social time”.*

## PEER INCLUSION

A common cause of anxiety for autistic people is a sense of being misunderstood and/or not accepted by non-autistic people. Thus, supporting autistic students with making friends and having others who accept and understand them is an important part of making the school experience manageable and enjoyable. One of our advisors noted school transitions were made easier by having neurodivergent friends that they met up with at the beginning of the school day. Peer inclusion could also be supported by assigning the student a friend or buddy, who helps with the morning routine.

## INCORPORATING A SPECIAL ITEM

Another suggestion is for the student to bring to school a comforting item. It is, however, important to note that often displays of difference can be ill-treated by peers. Thus, this needs to be included or managed in a considered way.

One of our advisors mentions:

*“When I was at school I had a pencil case that looked like a toy dog; this provided comfort while being cleverly disguised as a practical object you need for school which alleviated bullying. I also sometimes took along a small teddy bear that was small enough to keep in my pocket, and a stim toy that was small enough to look like a keyring decoration”.*



## PARENTS ROLE

Something else to acknowledge and consider is the relationship between the student and the person dropping off the student. Often parents’ reactions to leaving or saying goodbye to their child influences their ability to settle into the day. Consider, if there something the person doing drop off can do to ease transition anxiety? Are they staying too long? Are they not staying long enough? Does the person doing drop off have some anxiety around school drop off?

## GRADUAL INTRODUCTION/WITHDRAWAL

Our advisory members also suggest gradual introduction/withdrawal may be helpful for some students. A gradual introduction involves starting a student on reduced hours (e.g., attending for part days) and gradually building up the time they spend at school. Gradual withdrawal on the other hand, involves gradually reducing a support measure as the student becomes more comfortable, or settled. An example of this may be the introduction of a support person who stays with the student at school, and slowly the support person spends less time with the students as they adjust to the environment.

### **A note on varying attendance hours:**

*Section 42 of the Education and Training Act enables a student’s parent (or full-time caregiver where appropriate), their principal and the Secretary for Education to agree to vary hours as part of a transitional attendance plan when the particular needs of the student require this. The plan must be requested by the parents only. It must be considered by all parties involved to be in the child’s best interests, and evidence will be required from a medical professional. The plan can be for no more than six months duration but can be renewed once only for a further period of up to six months.*

*In general, transition times can often be a trigger for anxiety in autistic children, this along with the added pressures of the school environment can make school drop off challenging. Acknowledging your child’s worries and learning what strategies will best support them is key.*



Emily Acraman is a researcher for Altogether Autism.



# Autism and Education

## How Resource Teachers Help



Autistic students can often struggle in the educational setting but there is help available, particularly around transition, writes Nelson Bays' resource teachers **Fran Beullens** and **Cath Dyson**.

The Ministry of Education-funded Resource Teachers for Learning and Behaviour Service supports schools to meet the learning and behaviour challenges of students.

Highly skilled itinerant teachers in the service have a wealth of experience which includes an understanding of autism.

They are experienced classroom teachers who have completed a Post-Graduate Diploma in Specialist Teaching and they scour the latest research and evidence of best practice.

There are 40 RTLB clusters across Aotearoa New Zealand, servicing schools from Year 1 to Year 10.

The service is grounded in an evidence-based and whānau centred approach, ensuring that teachers, the student and whānau work together in a solutions-focused way.

Nelson Bays cluster manager Lyn Evans says the service enables students to participate in learning, putting the student at the centre and being responsive to various levels of neurodiversity.

This might be looking at the classroom environment and how modifications could enhance student achievement. It might be working with a whole school, providing professional development for staff around neurodiversity, including teachers, teacher aides and school leaders. It could be working at a systems-level to ensure inclusive practice is at the heart of a school's planning.

The support is culturally affirming, inclusive and

collaborative. If a school requests an RTLB service for a student, the whānau can expect to be at the centre of decisions made; plans are made 'with' the student and whānau, rather than done 'to' them.

"RTLB take on the role of tying everything together and ensuring our tamariki have personalised plans where all adults in their lives are empowered to support them." Karilyn Cribb, Learning Support Co-ordinator, Nelson.

### HOW CAN RESOURCE TEACHERS HELP?

Emma\* has had two positive experiences with the Nelson Bays Resource Teachers for Learning and Behaviour Service (RTLB).

The first time her daughter, Claire, had just received her autism diagnosis and her school discussed feeling ill-equipped to meet Claire's complex learning, social and sensory needs.

RTLB worked with whānau, teacher and key school personnel to develop a comprehensive plan for Claire's teacher, ensuring that Emma was part of the planning process.

"The four-way communication process has seen some fantastic outcomes, my daughter is beginning to have a much more positive experience at school, feeling more settled, heard and understood," said Emma.

There needed to be some fine-tuning of the initial plan the second time despite the fantastic work already being done in the school setting.

The resource teachers gathered student and whānau voices, conducted class observations and then created a new plan.

This enabled more brain breaks for Claire, incorporating daily piano playing - this helps her emotional regulation - and allowing her to play with Lego.

Claire's teacher said the knowledge brought to the meetings by RTLB around Claire's needs was very helpful.



“Claire will now tell me when a brain break is needed. The school purchased Lego for one of the brain break ideas. This has been very successful. Claire will often play with the Lego at lunchtime with other students.”

The service can also play a part in supporting whānau to work towards an autism diagnosis for a child.

This is often prompted by a school realising that a student has significant barriers to learning or it is simply unable to meet the child's needs.

Nelson's Leonel Bojorquez, 7, was having daily meltdowns and struggling to maintain peer connections at school.

His paediatrician diagnosed Leonel with attention deficit hyperactivity disorder (ADHD) but ruled out autism.

However, his mother Abby was convinced Leonel's challenges at school and home were reflecting another underlying challenge that had yet to be identified and called on RTLB to help.

“Working one-on-one with the teacher and our family, RTLB was able to gather vital information about Leonel and his daily school experience.”

This then led to a diagnosis of autism.

Even before a diagnosis happens, RTLB can be instrumental in enabling teachers to meet their students' needs and make positive change.

Melanie Savill, a resource teacher from Nelson Bays, describes how she supported a teacher prior to their student's diagnosis.

They worked together to introduce a predictable routine for the day to lessen the student's anxiety.

In using a 'When... Then' strategy, they encouraged the student to complete a task, knowing a preferred task could then be negotiated.

“Helping to train teacher aides to meet an anxious student in the morning and go over the upcoming daily activities can set them up for success,” said Melanie.

“Just knowing that someone was on our side made all the difference. The RTLB guided us in terms of the most suitable school – without that our child could've ended up in a school that would not have met her needs. It is also reassuring that we can access RTLB again when our daughter transitions to secondary school.” Suzanne Levey, parent.

## AUTISM AND EDUCATIONAL TRANSITIONS

As any parent of an autistic child knows, there are many types of 'Transition' in the educational context. Most pose considerable challenges.

Nelson Bays cluster manager Lyn Evans says unless the

student is completely prepared for the change, it can cause incredible upset.

### Typical transitions in a child's schooling are:

- The educational system itself - kindergarten to primary; primary to intermediate; intermediate to secondary.
- Changing classes at primary school e.g., Year 3 to Year 4 – new teacher, new students, new routines.
- Having up to seven transitions (between different subjects) in one day at secondary school.
- Daily – home to school and school to home.
- Diagnosis – from not having the diagnosis to being diagnosed with autism.

RTLB can provide support in any of these contexts.

One Nelson parent said having the service on board for her daughter's transition from primary to intermediate was “priceless.”

They oversaw the transition process from the outset, acknowledging that her daughter was “different” and ensuring that she received the best support.

RTLB's role was “validating and legitimising” her daughter's unique qualities, allowing them to shine in the ‘right’ school setting.

*“RTLB gave my child a voice and input into how school could be a more positive experience for him.”*  
Abby Bojorquez, parent.

### HOW CAN YOU ACCESS RESOURCE TEACHERS FOR LEARNING AND BEHAVIOUR SERVICE?

First talk to your child's teacher and ask for their thoughts.

In some instances, asking to meet with the school Special Educational Needs Coordinator or Learning Support Coordinator can be helpful to instigate the RTLB referral process.

Keep in close contact with your child's teacher throughout the process.

The assigned resource teacher will contact you and a meeting will be arranged.

Read 'A Personal Perspective' by Cath Dyson on the next page.



Fran Beullens (left) and Cath Dyson (right) have recently been diagnosed with attention deficit hyperactivity disorder and autism.



\* Some names have been changed



# A Personal Perspective

As a person recently diagnosed with autism I feel that I can offer a unique service to schools, students and parents in my role as Resource Teacher: Learning and Behaviour.

*Having gone through most of my life feeling different and misunderstood, I have genuine empathy for neurodiverse students.*

My schooling experience reflected that found in many undiagnosed autistic girls. I was quiet, compliant, a perfectionist and desperate to please. I was bullied and became even quieter. I have masked and coped throughout my life. Getting the autism diagnosis at 47 was life-changing.

I can speak with understanding, when working with teachers in meeting an autistic student's needs.

A recent example was a student who was struggling with the school day without breaks or down time. I know that feeling of 'being full' (as I call it); when my brain, literally, cannot take in anything more until I have a break. In sharing this with the student's teacher, I was able to speak from experience. This added weight and genuine understanding in meeting the student's needs and the support I was giving the teacher.

Perhaps the other biggest asset in my role is that my three children have also had an autism diagnosis.

The path to these diagnoses was not straightforward and as a parent I have gone through a range of challenges.

I have been the parent who is called into school due to my child's 'misbehaviour'. I have been the parent who has had to explain – again – that this behaviour is not intentional, nor does it reflect who my child really is.

I find that as soon as I share with a family that my own children are autistic, a weight is lifted from them. I can share my personal struggles and various challenges that each one of my children have experienced. A family can see that having neurodiverse children – and being neurodiverse yourself – does not have to be the end of the world. - [Cath Dyson](#)



Cath Dyson with daughter Sylvie

## Students' Education System Rights



Some of the biggest transitions we all experience as children are those in moving from one type of education to another, writes disability lawyer **Nan Jensen**. For any of these transitions, it is important to plan early and establish the right fit for the student.

[Our education system has a legal framework which provides specific rights for students and parents.](#)

We start with early childhood which is not compulsory but because providers receive Ministry of Education funding, they are obliged to follow certain rules and laws.



Providers, many of whom are private businesses, are not obliged to enrol any child but the Human Rights Act 1993 still applies.

This Act forbids discrimination on the basis of disability, but it also allows an exception in cases where 'reasonable accommodation' cannot easily be given.

In effect, this means that if a child needs additional support, they may deny enrolment because they cannot meet the child's needs.

Support in the form of education support workers and other specialists may be provided through the Ministry or one of a few other providers. This could be psychologists, speech-language therapists, physiotherapists or early childhood teaching specialists.

Primary school and the first two years of secondary school are compulsory.

Students must start school by age six and can leave after age 15 – but most students start at five, with some students remaining in secondary school until age 21.

If you choose to keep your child in early childhood education until they are six, any extra assistance available to them will be stopped when they are five unless you discuss this with the Ministry of Education and get it organised ahead of time.

The government claims all sorts of support is available at school, but before any transition, it is important you engage with the school and the Ministry of Education early to determine what support your child needs and what will be available.

Support and funding are supposed to be needs-based but there simply is not enough to cover all children and all needs and parents can be in a situation where they feel that they are constantly fighting and advocating for their child.

The Ongoing Resourcing Scheme (ORS) is the most sought-after funding because once your child has it, it cannot be taken away.

There are different levels of funding though and even when your child's funding is approved, the number of teacher aide hours are never enough, and these can be subject to change.

Applications are time-consuming to prepare, making it vital that the person preparing it has experience in completing them.

It is not uncommon to have to reapply several times, or ask for a review, before approval is finally granted.

Therefore, it is so important to get started early.

It is also easy to get in a conflict with school staff and the Ministry when you feel your child's needs are not

being met, but it is best to try to retain them as allies in advocating for resources for your child and their school.

The Act provides for an appeal process through arbitration – which is like a court case, but you have an arbitrator who decides the outcome instead of a judge.

The arbitrator is an expert in special education.

You can use the appeal process to appeal any decision by the Ministry that relates to special education (the Act still uses this term even though the Ministry talks about 'Learning Support').

The process is very stressful so you should only use it after having exhausted all other options.

Most appeals relate to ORS funding.

## SUSPENSIONS AND STAND-DOWNS

Suspensions and stand-downs are unfortunately a big issue for the autism community and generally for students with disabilities.

Recent research showed that autistic students were much less likely to be suspended if they had Ongoing Resourcing Scheme (ORS) funding. \*

The principal may only suspend because of gross misconduct or continual disobedience or if the student's behaviour could cause harm.

Stand downs are a period where the student may not attend class – up to five days per term and not more than a total of 10 days in a year – stand-down can also take place at school.

A suspension may only be for up to five days after which there must be a hearing.

It is important for parents and students to know their rights regarding this process because school boards often don't follow proper processes. Students have the right to natural justice.

This means several things. One is that the student has the right to tell their side of the story.

The principal should only suspend a student after considering all the circumstances, including any disability. Any incident needs to be fully documented and the student and parents must receive a copy of the report prior to the hearing, which must take place within five days of the suspension.

The school board representatives at the hearing must be independent – that is, they must not have a conflict of interest, such as a child who was involved in the incident. The board must consider the entire matter – including whether it was appropriate for the principal to suspend.

*Story continued on next page*



Once the board has heard all sides of the story, there are four options:

- to lift the suspension unconditionally
- to lift the suspension with conditions
- to extend the suspension
- or to exclude or expel the student.

I always recommend that people bring someone independent to any hearing. If the person is an experienced advocate, that is perfect, but anybody who is willing to take notes and be a 'witness' can play an important role.

You will probably be emotionally involved, so your witness is likely to hear things that you miss and they may be able to speak up if you suddenly lose your words.

Even if they say nothing, their notes can be valuable for reviewing the meeting and determining whether the process was done correctly and is fair and the board will be aware that a witness is present.

In my experience, many boards do not know how to conduct these hearings and make mistakes.

A recent newspaper article quoted a principal that described suspending students to attract more funding. This is a complete abuse of the suspension process.

### WHAT IS KIWI SUSPENSION?

Kiwi suspension is an unofficial exclusion.

This happens in secondary schools because schools that exclude students are required to accept a student who has been excluded from another school.

Some schools try to avoid this by encouraging parents to move their child to another school warning that the student is likely to be excluded if the suspension process is followed.

This is illegal and denies the student the right to natural justice. The school may try to make you think they are doing you a favour.

This practice is detrimental to students and results in incorrect suspension statistics.

### USE OF RESTRAINT

Restraint is only permitted in certain circumstances such as:

- breaking up a fight
- stopping a student with a weapon

- when furniture or other objects are thrown close to others who could be injured
- preventing a student from running onto a road.

### SEARCH AND SEIZURE

Search and seizure of student property has a prescribed set of rules and processes. In general, a school may not violate student privacy through routine search and seizure.

Any search must be based on a reasonable belief that the student has an item that is likely to endanger safety of any person or likely to detrimentally affect the learning environment.

Physical discipline is also forbidden.

### WHAT HAPPENS IN TERTIARY EDUCATION?

Tertiary education is not compulsory.

Most tertiary education providers try to accommodate students with disabilities, but my experience is the support they offer is often not suitable for autistics.

Again – the best way to achieve success is to find the right institution and meet the people that will be responsible for that area of study, as well as meeting the disability support team to discuss your needs.

### DEALING WITH DISPUTES

One ongoing complaint to the Ministry of Education has been about the difficulty in

making complaints and getting fair outcomes to disputes.

Families and students can feel quite powerless in these situations.

If the dispute is against the school, your first step is to follow the school's complaints process, which normally means escalating from the teacher up to the board, if necessary.

If you're still not satisfied, or if your complaint is against the Ministry, or another party, then some options are:

- complain to the Human Rights Commission (if the situation reflects discrimination because of a disability)
- complaint to the Ombudsman, who accepts complaints against government departments and organisations such as schools
- or Judicial Review, which is a High Court process – this option is costly and time consuming. You will also need a lawyer.





If your complaint is against a private provider or school, then you need to review the contract you signed on enrolment and speak to a lawyer.

Youthlaw is a Community Law Centre that specialises in the rights of young people and have considerable experience with Education Law. They may be helpful to you in preparing for a meeting.

The Education and Training Act contains a new disputes resolution process, but at the time of writing it is not operational. That is disappointing because people have been complaining about the lack of dispute resolution mechanisms for a long time.

### PARENTS' RIGHTS

The Education and Training Act allows a parent or non-student to be fined or imprisoned if they intentionally insult, abuse, or intimidate a teacher or staff member of a registered school.

So, it is important, even if you are upset, to speak respectfully to school staff.

I have not heard of any parents charged with this offence, but I have heard of parents being trespassed from schools.

A trespass is a serious issue, with the notice lasting for two years.

**YOUTHLAW 0800 884 529.**

*Nan Jensen is a lawyer specialising in disability law. She is a consultant with Quinlaw in New Plymouth. Practising from her home in Hamilton, she utilises technology to service New Zealand's disability community nationwide.*



*Nan has practised for almost 10 years, also providing legal education on Disability Law matters and acting as a director of The Disability Trustee, which provides trustee services to trusts with disabled beneficiaries.*

*\*Association Between High-Need Education-Based Funding and School Suspension Rates for Autistic Students in New Zealand | Autism Spectrum Disorders | JAMA Pediatrics | JAMA Network*



## The Stumbling Blocks of Tertiary Education

**Rachael Wiltshire** completed a degree at the end of last year, nine years after first embarking on tertiary study. Here, she discusses her tertiary education journey and considers some of the factors that would have made her transition to tertiary study easier.

If you had told me when I was in Year 13 that it would take me nine years to complete a degree, I wouldn't have believed you.

I had excellent academic results, scholarship offers to two universities and I'd spent time on university campuses as part of various science camps. As far as I was concerned, I couldn't possibly be more prepared.

I chose to move to Auckland for university, and it didn't take long to realise how very wrong I had been about my preparedness.

Three weeks after moving to Auckland, I flew home for the weekend and found myself in tears when I had to get on the plane back to Auckland, for reasons I couldn't fully articulate.

Things deteriorated from there.

I cried during lectures and developed such a fear of the dining hall at my hall of residence that by the second semester I was surviving entirely off foods I could keep in my room.

*Story continued on next page*



Despite these challenges, I did ultimately decide to return to Auckland the following year.

This time I was living in a studio apartment, which proved to be a much better living situation for me. That second year was successful, I was even happy to stay in Auckland over the summer to complete a summer studentship.

For some reason, however, things deteriorated again in my third year, to the point that I was unable to complete my second semester exams. Although I was doing a conjoint degree and had another year of study to go, I decided not to return to Auckland for my fourth year.

My scholarship had run out and that was the only thing keeping me in Auckland by that point. I moved home to Wellington, and whilst I did complete a couple of papers through Massey University with the intention of crediting them back to my Auckland degree, my heart was no longer in it.

Although I had actually completed enough papers to earn a BA, I chose not to formally graduate.

and ended up needing to take an extra year to complete the third year of the course.

However, I always felt supported by my tutors to take things at my own pace, and I'm super proud that I can finally say I have a degree (even if I don't have the cap and gown photos to prove it, thanks to Omicron!)

When I was in my final year at school, I assumed that I was ready for university because I was academically prepared. I assumed that because I had spent two or three weeks away from home at various times on science camp, I was prepared for living in a hall of residence.

I quickly realised that, for me at least, academic preparedness was probably the least important consideration in transitioning to tertiary study. This transition is a major life change. It may well be the biggest change you have ever been through, especially if you move to a new city for study.

There are a number of factors to weigh up when choosing where and what to study. In hindsight, I focussed too much on the prestige of the institution I wished to study at, and not enough on whether it was the right fit for me.



Here are three key factors that I wish I had given more consideration to in deciding my next steps after school.

### MOVING AWAY FROM HOME

Tertiary study is a big change from secondary school; you generally have a lot less oversight from your teachers and are expected to be more independent in reaching out for help.

Personally, however, I could have coped with

In Wellington I reconnected with my old dance school, first taking classes there, and eventually getting some teaching work. I realised just how important dance was in my life; attending dance classes had been one of the things that made living in Auckland easier.

I decided to enrol in a tertiary dance course in Wellington, and it is from that course that I finally graduated last year. That journey was certainly not without its challenges; it took me five years to complete a three-year course, in part because I had to have a year off for surgery, but also because I developed severe anxiety during the first lockdown

those differences; what made university study so challenging for me was that I moved to a completely different city for it.

Living in a hall of residence and living independently are both big transitions: for me, the social aspects of hall life, such as navigating where to sit in the dining hall, provoked major anxiety.

Whilst living in my studio apartment was definitely better, I still found things like planning and preparing meals difficult. Even now, I have to stick to a routine of what I will eat each day or I simply forget to eat!



Furthermore, moving to a new city meant I lost contact with all my social networks.

Some of those relationships would have changed simply due to leaving school, of course. My closest relationships during my school years were with my teachers, and whilst I wouldn't say I was close friends with any of my peers, I definitely enjoyed seeing them every day.

However, being in Auckland also meant I lost contact with my dance teachers and friends, and my relationship with family switched to being based mostly on texts and emails. Whilst I tried to make new friendships in Auckland by signing up for dance classes and joining university clubs, I couldn't replace the established relationships with people I'd known for years that I had left behind in Wellington.

On reflection, I think I would have been much more likely to succeed at university study if I had stayed in Wellington. This approach would have meant I could spread the changes out, perhaps I could have lived at home during my first year, and then tried flatting once I was more used to university study. It would also have meant I could continue my dance classes and see my family regularly.

### CLASS SIZE

One of the things I have learnt about myself during my time in tertiary education is the importance of having strong relationships with my teachers.

I found I much preferred small class sizes, my dance course is an example of this, but even at university I enjoyed my language classes the most, because the small class sizes meant you actually got to know your tutors.

In a class where everyone knows you, you automatically get some social interaction in your day, whereas if you only do large lecture classes, it is quite easy to go whole days without talking to anyone!

Perhaps more importantly, when your teachers know and value you as an individual, it is much easier to ask them for accommodations; people who know you are generally willing to work with you to find a way you can meet the requirements of the course, whereas in a larger class you are often just a number and it can be harder to convince people that you do need accommodations.

If I ever enrol for further tertiary study, small class sizes or the ability to work one-on-one with the teacher will be the key thing I look for in a course.

### ROUTINES

Routines are incredibly important to me in managing my day-to-day life.

However, I struggle with establishing my own routines; I get very anxious when I have large amounts of unscheduled time.

This manifests itself in the workplace, where I have never survived a typical office job for more than about eight weeks, I tend to do much better with jobs like teaching, where the routine is already pre-planned.

It also manifests itself in tertiary education: one of the things I liked the most about my dance course was that it was like school, with most of our time spent in scheduled classes.

In contrast, the fact that a day at university could involve just one or two classes and large amounts of unscheduled time, plus the fact that no two days were ever the same, made having any sort of routine very difficult. If I ever were to return to university-style study, I would do so part-time so that I could also work. If I had work to create a sense of routine in my days, I would be better able to cope with the unstructured nature of university study.

Of course, the weight you are able to give these factors when making decisions about your own tertiary education does depend on what you want to study; if you want to do medicine, for example, your only choices are Auckland or Otago and there is nothing you can do about the large class sizes of the first year courses.

It is important, however, to give weight to the things you know will help you to learn effectively and with the least amount of stress possible.

**Remember, too, that tertiary education will be there waiting for you when you are ready for it; it truly is a journey that you can take at your own pace.**

I doubt I would have been successful on my dance course had I enrolled in it straight out of school, as I definitely wasn't ready for the emotional demands of the course.

Windy as the road has been, my tertiary education journey to date has been the right path for me. I hope that all autistic students are eventually able to find their own right path, and that by considering the factors discussed here, you might be able to avoid some of the stumbling blocks I tripped over.



*Rachael Wiltshire lives in Wellington and found out she was autistic when she was 12. She has been passionate about autism advocacy ever since and has spoken at several conferences. She is an autistic advisor for Altogether Autism.*





# Supporting the Transition to Adolescence

The teenage years can be a particularly difficult transition to move in to, especially as an autistic teenager, write **Emily Acraman** and **Chrissy Frost**.

Adolescence can be a particularly vulnerable time for autistics.

They may have a greater sense of the fact that they are 'different' to others. They may feel acutely aware that they experience the world differently to their peers.

It can be exhausting trying to communicate and fit in socially especially if they are being bullied and excluded at school.

High school presents added pressures, including an increased demand for schoolwork, fewer formal supports, and a greater focus on students' future options.

Hormonal changes and puberty can be a roller coaster and overall, the social and practical demands of the neurotypical world increase.

Autistic teenagers may exhibit challenging behaviour, may respond inappropriately to social cues, be unable to perform skills needed for independence and be at an increased risk of mental health problems (Spectrum, 2021).

## BEHAVIOUR IS COMMUNICATION

The remodelling of the brain during puberty which prompts physical changes, also leads to intensifying emotions and rapid mood changes. For autistic adolescents, this appears to be exaggerated (Spectrum, 2021).

Often parents report an increase in challenging behaviour, or behaviour that is difficult to manage. At home you may see your teenager let their emotions out in extreme ways and may see an increase in meltdowns. Often for autistic teens, home is the place they have space to or feel safe enough to do so.

Understanding that challenging behaviour or emotional outbursts are a form of communication may make them easier to confront. Physical behavioural outputs can be regarded as a form of communication.

For autistic teenagers, these outbursts may be more meaningful than verbal language.

One of our autistic advisors speaks of their teenage years during which they often threatened self-harm. They explain there were not suicidal but were trying to communicate they were having a difficult time and that more support was needed.

It may be helpful to think of these outbursts and meltdowns as though you are both communicating but that you are speaking different languages. Trying to understand what is being communicated through these meltdowns will help you shape your response to them.

## SOCIAL CHALLENGES

During the adolescent years, autistic teens usually have a greater sense of what they might be 'missing out' on.

Feeling left out or being socially rejected by peers can have huge consequences for ones' wellbeing and sense of self. It is generally during this time that bullying accelerates, and autistic teens can experience a lot of ostracism.

For girls, this is particularly apparent. Peer support is of the utmost importance during the teenage years. Only other autistic teenagers or adults can provide true empathy, insight and understanding on what it is like to be an autistic teenager. One of our autistic advisors mentions:



“As much as parents may be trying their best with the knowledge they possess, it can’t really be empathetic support (unless perhaps a parent is neurodivergent) and an impartial peer can have far greater impact than parental support.”

Peer support also offers teenagers the opportunity to feel a sense of identity, belonging and that they are not alone. It allows opportunities for them to see what challenges other teens have overcome, what solutions they found the most useful and what a positive future could look like. Autistic peer groups, groups based around preferred interests (tabletop gaming, sports, art etc), peer led blogs and autistic social media influences can all be helpful supports to join in or follow along with for autistic teens.

It is critical during this time to support autistic teens to develop a sense of belonging and to identify the value they bring to the people around them (Downs & Holden, 2020).

Peer mediation can also be a helpful strategy for navigating the tensions between parents and autistic teenagers. This involves facilitating and translating the point of views, thoughts, and feelings of both the parents and the teens so that they can understand each other. When it feels as though we are speaking different languages to each other it is vital to have someone translating for us.

## ENCOURAGING COOPERATIVE BEHAVIOUR

It can be tricky navigating behavioural expectations, boundaries and consequences with our teenagers.

Parents need to expect that teenagers will push boundaries, as it is their job to do so.

Autistic teens often like clear routines and structure in their lives and changes in these routines can cause anxiety and challenging behaviour. Giving effective instructions, setting limits and sticking to these, and offering them a choice in what they can do can all help increase cooperative behaviour.

If you start to see a pattern of challenging behaviour from your teen, try to investigate what may be causing it.

They may be feeling overwhelmed, have difficulty understanding what was expected of them, be feeling anxious and stressed or possibly suffering from sensory overload.

When you take some of these causes into consideration, you may be able to change things in the environment that can help your teen cooperate with you.

## SHARING CONTROL

We all like to feel in control of our life and this is no less true for teenagers. Try to let your teens feel as though they have some control through input and value in the family dynamics. Setting some shared

goals, expectations and consequences for behaviors could be an option to explore. When teenagers have choices, they learn to make decisions and think for themselves. This is good for their self-esteem as well as their ability to cooperate.

## MAINTAINING RELATIONSHIPS

They may not admit it, but teenagers need their parents now, just as much as they did when they were younger. Aim for regular one on one time with your teenager.

This might be an activity like going for a walk together, cooking dinner together, going to the library, or finding an activity that they enjoy and joining in with them.

Try to find an activity where you are doing something alongside each other without looking directly at each other as this can make it uncomfortable and potentially harder to talk.

Limit your expectations of these sessions, they may not communicate at all. But by spending one on one time, you are letting them know that you are available for them, should they need you.

One of our autistic advisors comments:

“Maintaining the relationship between parents and teenagers is key- as a teenager I had regular one-on-one time with both my Mum and my Dad (supermarket trips with Mum and walking the dog with Dad) and I think that was really important in maintaining a close relationship with both of them. There was no expectation to talk about anything deep, or even to talk at all, but often towards the end of our time together I was ready to open up about the things I was struggling with.”

If your teen is withdrawing themselves from people and their family, you could schedule a weekly family fun time that they could help to organise, such as a regular games night.



Emily Acraman (above)  
and Chrissy Frost (below)  
are researchers for  
Altogether Autism.



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# Advocating for Disabled People's Rights



New Zealand law allows parents or court-appointed guardians the legal authority to make decisions for children, writes disability law specialist **Nan Jensen**.

There are situations where children under 18 can make their own decisions or at the very least have their opinions considered.

However, the Privacy Act 2020 and its Health Information Privacy Code has confused this issue even more because it states that health information about a child 16 years old or sometimes even younger must not be released to other parties without the express consent of the child.

This can be difficult in situations where the child has a disability and their communication is limited or unclear.

The Privacy Act provides no solution to this situation, and I am often contacted by parents who are unable to access their child's health information due to the understandable difficulty that health practitioners have in interpreting the law.

The new Act also has significant penalties for parties who breach the Act – providers are understandably cautious and afraid of incurring a fine.

Thankfully, the Health Act 1956 and the Health Information Privacy Code define a person's 'representative' as the parent or guardian for a person under 16, and where the child is over 16, where the person is "unable to give his/her consent or authority, a person appearing to be lawfully acting on that individual's behalf...".

Parents and guardians do lawfully act on behalf of their children until the age of 18. Section 22C (3)(b) of the Health Act allows health information to be provided by such a 'representative' for the purposes of relevant

section of the Privacy Act, as does Rule 11(1)(b)(ii) of the Code.

So, parents and guardians should be able to obtain their child's health information if the child is under 18 and is unable to give consent or authority. It is unfortunate that it is so complicated for families who cannot get their child's medical information, despite the child's inability to understand or give any meaningful authority to another person.

Once a person turns 18, the parents are no longer the guardians, and so the adult has the legal authority to make their own decisions.

Our law provides that everyone, regardless of diagnosis, IQ score or anything else, has the capacity to understand and make their own decisions unless or until they have been deemed to lack that capacity.

The law that addresses this issue is called the Protection of Personal and Property Rights Act 1988. This Act provides for a variety of potential court orders to allow decisions to be made for and by (with support) adults who partially or wholly lack the capacity to understand these decisions. We will cover this later in the article.

## SUPPORTED DECISION MAKING

The concept of supported decision making comes from the United Nations Convention on the Rights of Persons with Disabilities.

UN conventions are aspirational documents that countries sign on to. By signing and ratifying a convention, the country commits to incorporating the principles of the convention into domestic law.

New Zealand has signed and ratified this convention, and while aspects of the Protection of Personal and Property Rights Act do reflect some principles of the convention, it is widely recognised that a number of



our laws around adult decision-making capacity need review. The law is currently being reviewed by the Law Commission, but little progress is evident.

Any changes are likely to still be years away.

Supported decision-making is not actually named in the United Nations Convention on the Rights of Persons with Disabilities, but it does specify that adults should be supported to make their own decisions, rather than having their decision-making authority replaced by a substitute decision maker.

The Act does stipulate that anyone appointed under the Act is obliged to encourage the disabled person (the Subject Person) to exercise and develop the capacity they have. It is widely agreed amongst practitioners and professionals that people acting on behalf of others under this Act are expected to support the Subject Person's decision making and only make a decision on behalf of the person if they are wholly unable to make or communicate their own decision, or if the decision they want to make is so completely against their best interests that the person acting for them is obliged to intervene.

There are currently no mechanisms for checking how these roles are carried out, and there may be better ways to incorporate supported decision making into the legislation, to ensure the Subject Person is being properly supported and that there is accountability for those providing support.

## WELFARE GUARDIAN/PROPERTY MANAGER OR ADMINISTRATOR

Where a person totally lacks capacity to understand the nature and consequences of their decisions about any aspect of their personal care and welfare, the Court can appoint a Welfare Guardian. Welfare guardians have the authority to support decisions about personal care and welfare – such as medical consent and where the Subject Person is going to live.

Property managers and administrators can be appointed to manage property. Property is not just land and buildings, it is everything a person owns, including bank accounts, investments, KiwiSaver, WINZ income etc.

These roles also normally have the authority to communicate with IRD, WINZ, KiwiSaver providers, banks and so on.

These applications cannot be filed before the person turns 18, so there will inevitably be a period where only informal support can be given. The first order will be for up to three years. After that, five years can be requested but that is the longest an order can last.

A lawyer is appointed for the Subject Person and they act while the application is underway. Once the order is made, the lawyer is no longer involved until there is an application for new orders. No one checks how the appointees are carrying out their roles until an application for renewal of orders is made.

## ENDURING POWERS OF ATTORNEY

An attorney, in New Zealand, is a person who acts on behalf of another person (the donor of the power).

A power of attorney is a document where the donor, who has capacity, appoints another person as their attorney. An Enduring Power of Attorney (EPA) has its name because it 'endures' past the point where the donor loses capacity. But to give that power away, the donor must understand what the document is about – the document only becomes active when an event occurs resulting in loss of capacity by the donor.

EPAs also come under the Protection of Personal and Property Rights Act.

The attorney roles are divided between personal care, welfare and property, just like the roles of Welfare Guardian and Property Manager.

In fact, being an attorney is like holding one or both of those roles. The two big differences are:

- a) The Court appoints Welfare Guardians and Property Managers while the donor chooses their own attorney(s)
- b) Court orders have expiry dates and are reviewed. EPAs are valid forever unless the donor revokes them.

Many autistics will be able to understand an EPA document enough to give the power away. If they do not have that capacity, then they cannot give Power of Attorney.

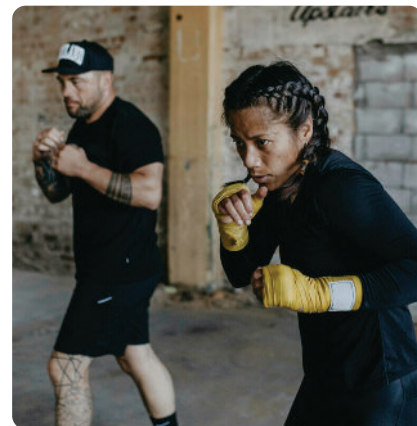
Enduring Powers of Attorney are prepared and witnessed by a lawyer or registered legal executive.

The lawyer or legal executive must satisfy themselves that the donor has the capacity to understand the document.

Attorneys have the same obligation as Welfare Guardians and Property Managers/Administrators to do supported decision making.

As EPAs are not renewed and no one checks that the attorney is carrying out their role properly, this means that there is sometimes serious abuse of donors.

Another risk is that a vulnerable person can be taken to a new lawyer and coerced into making EPAs in favour of a new 'friend.' One would hope the lawyer would refuse to act in such a situation, but a determined person is likely to lawyer-shop until they



*Story continued on next page*



find a lawyer willing to prepare and witness documents.

People First have excellent 'easy-read' resources about a number of topics, including EPAs. I use these when discussing the making of EPAs with someone who needs it described in a simpler way.

### HEALTH AND DISABILITY COMMISSIONER

The Health and Disability Commissioner Code of Consumer Rights contains a provision in Right 7 that allows family members and other interested parties to be involved in the care of a disabled person despite not holding a Court order or EPA giving them authority.

The provider of care must follow a particular process to use this provision, and big, ongoing decisions (such as placing someone in a nursing home) cannot be made using this provision.

*You can access a copy of the code on their website.*



*Nan Jensen is a lawyer specialising in disability law. She is a consultant with Quinlaw in New Plymouth. Practising from her home in Hamilton, she utilises technology to service New Zealand's disability community nationwide. Nan has practised for almost 10 years, also providing legal education on Disability Law matters and acting as a director of The Disability Trustee, which provides trustee services to trusts with disabled beneficiaries. She is a member of the Altogether Autism Advisory Group.*

## Voices from our Yoga Club



Yoga Club is by and for autistic people. **Nicolina Newcombe** writes about how they use restorative yoga, basic breathing methods and yoga nidra to build stronger connections to their bodies. Yoga Club is informed by tradition and inclusive for the group of Voices from the Spectrum members.

**I have enjoyed** yoga for many years as a non-competitive opportunity to engage in slow and accurate movement. It was only since my autism diagnosis that I came to value yoga as having the capacity to increase my awareness and help me regulate my emotions. After witnessing someone who communicates differently being excluded from yoga, I set a goal to create an inclusive yoga class where people can stim, make noises, and take breaks.

### BECOMING A YOGA TEACHER

I was fortunate to go to Anahata Yoga Retreat in Tākaka, Golden Bay and certify as a yoga teacher in the Bihar tradition. The Bihar tradition emphasises parasympathetic nervous system activation, using isolated movements that are simple and gentle enough to be completed without discomfort. Unlike other forms of yoga that require standing and strength, we rest and relax.

### STARTING YOGA CLUB

I did my yoga teacher training practicum with fellow Voices from the Spectrum members, a peer-support group run by and for autistic adults in Hamilton. The feedback was so positive, like when Sarah said, "it helped totally relax me and get rid of the physical and



mental tension I carry with me most of the time”, and Barbara said, “my breathing has felt more consistent”, that we decided to start Yoga Club.

To make Yoga Club as inclusive as possible, members are sent a PowerPoint presentation with photos of the yoga studio space and information about Yoga Club to give them the best idea about what to expect. We meet in a dedicated studio so we have a private clear open space with no other distractions. The studio has a comfortable lounge attached where we can meet up before and after Yoga Club to socialise. We talk about what is going well and what we want to do. Finally, like most Voices from the Spectrum groups, Yoga Club is free.

## POSSIBLE BENEFITS

Autistic people might derive benefits from yoga. We are much more likely to experience interoceptive challenges. This means many of us find it hard to read what is happening in our bodies based on cues like pain, temperature and blood pressure. Interoception is part of regulating emotions. Becoming more aware of our internal physiology contributes to managing anxiety and improving our sense of wellbeing. We believe consciously practising interoception in the controlled environment of a yoga studio supports engaging with sensations in the everyday world.

## WHAT WE DO AT YOGA CLUB

At Yoga Club, we practise things like feeling how air moves around our lungs when we raise our arms in different directions, experimenting with abdominal pressure, and listening to our heartbeat before and after asana.

Asana, such as extending our fingers out wide, rotating our wrists, or bending and straightening our elbows, are coordinated with our breath. We also hold relaxation poses for around two minutes. Ample use of bolsters and other props like blocks and blankets ensure our whole bodies can let go and be held by the surfaces beneath us. A key aspect is resting between practices to notice any changes in our bodies.

We do yoga nidra at the end of each session. Yoga nidra is a guided meditation with eight stages, including personal intention, systematically bringing attention to each body part, counting our breaths, imagining sensations, and visualisations. We practice with minimal stimulation, laying on our backs with our feet apart, hands clear, and eyes closed.

These activities develop interoceptive recognition and accuracy by focusing conscious awareness on one element of the body at a time, such as a joint, connection point, breath, or pulse.

## MEMBER STORIES

Yoga Club is “hugely significant” for Barbara as she has a breathing condition. “I like the gentleness of it and the gentleness of using my limbs”, she said.

Barbara tried yoga when she was young but gave up. However, “Yoga Club makes me feel really comfortable and welcome and encourages me to attend”. The best part of Yoga Club for Barbara is “matching my breathing with my movements; you would think it would be easy but it is really difficult”.



Nicolina Newcombe

Gaby is practising yoga for the first time at Yoga Club. He said, “my favorite part is being so relaxed I fall asleep. It is a fulfilling experience to focus on nothing but myself”. Gaby appreciates having our own Yoga Club. “It is important for us that we have our own space”, he said, adding to the positives, “there are no expectations”.

Sarah felt awkward and self-conscious doing yoga in the past but feels physically and socially comfortable at Yoga Club. “There is room to be ourselves without fear of doing the wrong thing”, she said. She has found our approach useful, saying, “it focuses on connection to the body rather than pushing the body to extremes”. “I really appreciate the ritualism in the way movements are timed to our individual breathing, the repetitions, and the familiarity of the structure of the session”.

## PERSONAL REFLECTION

I feel a deep sense of peace and satisfaction when teaching yoga to other autistic people. The challenges have been making sure people with very limited flexibility can take part, and encouraging people to visualise the practice. It is amazing to know we are developing a distinctive yoga practice, informed by tradition and constantly improved on by feedback from our members. I hope this is only the beginning and I agree with Sarah when she said, “it feels like a journey to calmness”.

> Nicolina Newcombe (DipJ, BA, GradCertNFP, MMPD) is an autistic yoga teacher and is currently completing her PhD in Education. ORCID 0000-0003-1833-6082.

> David Nixon is an autistic photographer who competes in Special Olympics and loves ten-pin bowling. Check out David Nixon Photography on Facebook or @d.n\_photography\_nz on Instagram.

> Te Pou have generously supported Yoga Club with a Disability Consumer Leadership grant.

> Sun Salute Yoga Studio have generously provided Yoga Club with free and reduced rate studio hire.

### Further reading:

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# INTERESTED IN AUTISM?



Come to our FREE presentation  
**BRAIN, BODY & BEHAVIOUR**



This workshop offers insights into the biology beneath behaviour and a compassionate approach that supports understanding of emotions and the development of self-regulation skills in children. It draws on information from Mona Delahooke's book 'Brain-Body, Parenting', as well as other sources. This workshop is for parents, whānau, educators and anyone seeking deeper understanding of autistic and neurodivergent children and ways we can support them.

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